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REPORT

Patient and Family Members Perspectives on Radioactive Iodine Treatment

by

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and
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PATIENT AND FAMILY MEMBERS PERSPECTIVES ON RADIOACTIVE IODINE TREATMENT

A report prepared by Petrina McGrath, RN, MN(c) and Margaret I. Fitch, PhD under contract to the Atomic Energy Control Board.

ABSTRACT

This report documents the findings of a survey of patients who received radioactive iodine therapy and their family members. The main objective of the survey was to gain an understanding of the experience of receiving radioactive iodine from the patient and family's perspective. The data from this study helped to inform the ARCP and GMA as they developed AC-9 – Principles of the management of radionuclide therapies.

A survey was distributed to 700 patients and family members through physicians at 8 sites across Canada. Locations included: Newfoundland, Nova Scotia, Ontario (2 sites), Quebec (2 sites), Manitoba and British Columbia. A total of 190 patients and 140 family members returned completed surveys. Data was analyzed separately for individuals treated as inpatients and those treated as outpatients.

The results of the survey provided a perspective from patients and families about their experiences regarding radioactive iodine therapy. The data indicate variation in patients' and family members' perspectives about how precautions are to be implemented. Both patients and family members expressed the desire for more information regarding many aspects of the treatment experience. The results have implications for the development of patient information, continuing education (in particular in the areas of precaution), the provision of access to supportive and counselling services, and the importance of looking at the individual situations of patients and their families.

POINTS DE VUE DU PATIENT ET DES MEMBRES DE LA FAMILLE SUR LE TRAITEMENT A L'IODE RADIOACTIF

RÉSUMÉ

Le présent rapport rapporte les résultats d'un sondage mené auprès des patients qui reçoivent un traitement à l'iode radioactif et des membres de leur famille. Le sondage avait pour objectif principal de mieux comprendre l'expérience que vivent le patient et sa famille. Les informations contenues dans ce rapport ont aidé le CCRP et le GCM a rediger document AC9 *Principles of the management of radionuclide therapies*.

Un questionnaire a été distribué à 700 patients et membres de leur famille par les médecins à huit centres de soins au Canada répartis comme suit : un à Terre-Neuve, en Nouvelle-Écosse, au Manitoba, et en Colombie-Britannique, deux en Ontario et deux au Québec. Au total, 190 patients et 140 membres des familles ont rempli et retourné le questionnaire. Les données sur les patients hospitalisés et les patients externes ont été analysées séparément.

Les résultats du sondage ont révélé les points de vue des patients et des familles sur leur expérience à l'égard de la thérapie à l'iode radioactif. Les données indiquent un écart entre le point de vue des patients et celui des membres de leur famille quant à la façon de mettre en oeuvre les précautions. Autant les patients que les membres de la famille ont exprimé le désir d'obtenir plus d'informations sur de nombreux aspects du traitement. Ces résultats ont une incidence sur la préparation de l'information aux patients, l'éducation permanente (surtout en matière de précaution), l'offre de services de soutien et de consultation, ainsi que l'importance de considérer la situation de chaque patient et de sa famille.

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EXECUTIVE SUMMARY

The purpose of this project was to gain an understanding of the experience of receiving radionuclide therapies. The work was completed for the Atomic Energy Control Board of Canada to help inform the development of principles for the management of radionuclide therapies. Patients receiving radioactive iodine (I^{131}) and their family members were selected as the sample because of the large number of patients treated with I^{131} and because the precautions taking during I^{131} therapy have been used as a model to guide the approach to other radiopharmaceuticals.

Data were gathered through the use of a national survey distributed to patients and their family members. A total of 190 patients and 140 family members returned completed surveys. The survey elicited information regarding perspectives concerning diagnosis, treatment, precautions, problems experienced, assistance received and selected demographics. Data were analysed separately for individuals treated as inpatients and those treated as outpatients.

The patients who responded to the survey reflected a well-educated, Caucasian sample. The majority of the respondents had been diagnosed within the past three years. Thirty-six percent experienced malignant disease. Approximately half (n=100) of the respondents received treatment as an outpatient. The majority of respondents were satisfied with the communication style of the health care professionals with whom they came in contact. The majority of respondents rated information about their medical condition, tests and procedures, treatment choices and side effects as very important.

No more than seventy-two percent of the respondents indicated feeling satisfied with the information they had received. Topics for which the lowest proportion of respondents indicated satisfaction were how to arrange to speak with another patient in the same situation, availability of counselling services, emotional effects and diet and nutrition.

Respondents who received treatment on an inpatient basis reported experiencing more symptoms than those treated on an outpatient basis. These differences are likely related to the type of disease treated on an inpatient and outpatient basis. The most frequently reported symptoms for the inpatient group were fatigue (63%), dry mouth (52%) and feeling down or depressed (51%). Outpatients reported fatigue (56%) and anxiety (52%) most frequently. Few respondents reported receiving adequate help for the symptoms they experienced during their treatment.

Both inpatients and outpatients reported variation in precautions implemented during and following their treatment with radioactive iodine. Inpatients reported the most difficulty with precautions regarding the following: being unable to do the things the patient usually does (42%), being off the thyroid medication prior to treatment (41%), being unable to get close to children or family (27%) and being unable to have visitors (27%). For the outpatients, the most difficult aspects of the precautions were being unable to get close to family members or children (29%) and being unable to do the things the patient normally does (24%). Both inpatient and outpatient respondents indicated similar concerns about going home after their treatment: worry about what the radiation will do to the rest of their bodies, concerns about whether the radiation is gone and concerns about others receiving a dose of radiation.

Family members also reflected a well-educated, Caucasian group. Approximately half (n=68) had a patient treated as an inpatient. Overall, family members reported satisfaction with communication styles of the various health care professionals with whom they had had contact. The majority of family members indicated information about medical condition, tests and procedures, treatment choices and side effects were important for them as a family member to know. Approximately half of the family members indicated they were satisfied with the information they received across all topic areas.

Family members experienced a range of issues themselves during the interval surrounding the radioactive iodine treatment. These issues included anxiety, feeling apart or separated from patients, fear and feeling down or depressed. Family members reported considerable variation regarding the amount of assistance they received for these difficulties.

Family members reported variation in the precautions observed during the patients' treatment. The precautions family members of inpatients experienced difficulty with included the patient being off thyroid medication before treatment (49%) and the patient being in hospital (47%). The family members of outpatients reported difficulty with the patient being unable to get close to the family and children (21%). With regard to the patient returning home after treatment, family members expressed concern about whether or not the treatment worked and whether the radiation was gone from the home environment.

Patient and family members expressed the need for information to help in preparing for hospitalization, treatment side effects and precautions as well as preparing the home environment following treatment. Additionally, patients and family members expressed a strong desire for access to support services and contact with other individuals who have undergone the experience of receiving radioactive iodine.

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A. INTRODUCTION

Radioactive Iodine (I^{131}) has a long established role in the treatment of hyperthyroidism and thyroid carcinoma (Group of Medical Advisors, 1993). There are approximately 13,000 patients treated with I^{131} for thyrotoxicosis or thyroid cancer in Canada per year (Dr. Dreidger, March 4th, 1998, personal communication). When treated with radioactive iodine the patient becomes a temporary source of ionizing radiation to other persons, with whom they come in close proximity, thus certain protective measures have been established to protect those who routinely come in contact with the patient.

Up until now, radioactivity levels have been utilized to determine if a patient requires hospitalization and isolation precautions. It has been the standard practice for many years to admit a patient simply to quarantine them from others until the level of radiation decayed is at a predetermined level (i.e.1.1 GBq for I^{131} therapy). This is followed by specified precautions which patients are instructed to take at home to further isolate themselves from others (Group of Medical Advisors, 1993). The set limits and the assumptions which underlie the usage of standard limits have come under question recently by a number of authors (Barrington et al., 1996a, Barrington et al., 1996b, Carey, Kumpuris, & Wrobel, 1995, Culver & Dworkin, 1992). This practice has raised questions about the best way to treat patients, particularly due to the growing body of literature on the real hazards to the public and the context of current hospital bed utilization issues, as opposed to using the worst case scenarios to dictate guidelines.

There has also been an increased awareness by professionals of patients' rights and responsibilities in their treatment and care. Along with an increased interest in looking at each case individually examining both the safety to the public, and individual needs of the patients and their family, as opposed to one standard approach (AC-9, 1999).

In 1997, the Atomic Energy Control Board (AECB) Advisory Committee on Radiological Protection (ACRP) and the AECB Group of Medical Advisers (GMA) formed a Joint Working Group (JWG-10), to develop a document called AC-9, "Principles of the Management of Radionuclide Therapies". After reviewing the safe

management guidelines in other countries, current research and trends in health care, this group has developed principles for managing the potential exposure to the family, clinical support staff and the public from patients who have received therapeutic doses of radionuclides (AC-9, 1999). Currently there are guidelines in place, but they are used inconsistently across Canada. It is anticipated that any new guidelines produced by this working group will serve as a comprehensive and uniform guidance for all Canadian Medical Institutions performing new and established radionuclide therapies (AC-9, 1999).

An important part of the group's undertaking is gaining an understanding of what the current experience is for patients receiving radionuclide therapies and the potential impact, both positive and negative, to the patients and their families, if changes in the guidelines were to occur. The AC-9 recognized the importance of having an understanding of the patients' and families' perspective in relation to the current treatment. Currently there is a lack of information of what the current experience of isolation is for patients and what impact this has on otherwise healthy individuals and their families. The literature on radionuclide therapies is heavily based on the health care professionals' perspectives and provides very little information on what patients identify as their needs and concerns.

This lack of information regarding the patients' and families' perspective of receiving radionuclide therapy stimulated this project. The members of the AC-9 thought it was important to have a clear sense of what patients and their family members experience under the current practices and their perceived needs in regards to potential changes in future practice. Such an understanding has the potential to influence the nature of future recommendations. Hence, the purpose of this project was to gain an understanding of the experience of receiving I^{131} treatment from the perspective of the patient and family.

1. Background Literature

When people face illness in their lives, there are often accompanying fears and uncertainties. Whether the diagnosis is of a malignant or non malignant condition, the view that individuals held of themselves of unlimited potential now has limitations and restrictions. The diagnosis of disease often involves treatment plans, procedures,

medications, and increased exposure to different health care professionals, and in some circumstances hospitalization. These factors provoke additional concerns and worries, all of which add to the impact felt by the patient and his/her family.

For many patients receiving radionuclide therapies, there is also another element that is experienced, that of protective isolation. Knowles (1993) indicates that there may be a difference in the experience of isolation between those for whom isolation is initiated for the protection of the patient versus those patients in whom isolation is imposed to protect others, as is the case with patients receiving I^{131}. Isolation is not an experience that most individuals voluntarily seek out. When isolated the patient remains physically, socially and emotionally concealed from the external environment. Therefore, it is important to investigate the impact of isolation, particularly when the patient's emotional well being may be compromised. While not always necessary, it is common for patients who are in isolation to experience limited frequency and duration of contact with health care team members and family (Jenner,1990). Very little research exists to help the health care professionals understand the experience of isolation from the patient's perspective and to use the understanding to provide care for each individual (Gaskill, Henderson & Fraser, 1997).

Trying to understand therapeutic choices and concerns both post treatment and following recovery were sited by volunteers at the American Thyroid Foundation as common concerns which lead patients with thyroid disease to ask for help (Wood, 1998). Frequently reported concerns specific to radioactive iodine were reported by the Foundation to include fears that radiation is dangerous to oneself, or to the rest of the family, and fears that the treatment is a risk to the health and well-being of future children (Wood,1998). Volunteer staff cited the following reasons for individuals' calls to the Foundation: wanting to talk to someone, feeling afraid, being too embarrassed to ask their physician to repeat explanations, and family members not understanding what the physician has told the patient (Wood, 1998).

It is reported in the literature that patients' experience various symptoms related to thyroid hormone withdrawal. These symptoms may include feelings of anxiety, depression, loss of concentration, or physical symptoms such as appetite changes and

muscle cramps. While these symptoms may be profound, severe and debilitating (Dow, Ferrel & Anello, 1997a, 1997b), it is not clear in the literature how the experience of isolation and I^{131} treatment impacts these already distressing symptoms or what is helpful to patients during treatment to help them contend with the above symptoms.

A number of studies with different patient populations have shown that adequate symptom control, available support services, information and communication with health care team members and family are important to persons experiencing illness (Rieker, Clark & Fogelberg; 1992, Gray et al. 1998,1997a, 1997b). Although experiences of illness often are shared across patient groups, the unique needs of patients receiving radioactive iodine are generally not known. It is also important to be aware that although there are often common patterns of response we may observe in patients being treated for the same illness, each patient and family's unique situation is framed by highly personal life experiences, values and beliefs. Policies and procedures must be flexible enough to carefully balance safety with the individual needs of patients and families.

2. Methods

2.1 Sample

Patients receiving radioactive iodine (I^{131}) and their family members were chosen as the sample populations for this study. The inclusion criteria for patients were individuals over the age of 12 years, who had either a malignant or non-malignant diagnosis, and had been treated with any dose level of I^{131}. This group was chosen because of the large number of patients treated with I^{131}, and because the precautions taken during I^{131} therapy have been used as a model to guide the approach to other radiopharmaceuticals, due to the combination of gamma ray emissions as well as the possibility of contamination of the environment. The patient selected one family member to participate in this study.

2.2 *Instrument*

The data for this study were gathered through the use of a national survey distributed to individuals who had received I^{131} and their family members. To ensure that the survey tool would be reflective of the patients' and families' experience of I^{131} treatment, the researchers conducted 21 semi-structured interviews with patients who had received treatment, in either an inpatient or outpatient setting. Analysis of the interview data focused on the identification of the main content and themes across all of these interviews. These initial interviews provided descriptions of the experience of receiving I^{131} treatment and facilitated the identification of content areas for the survey questions.

Following analysis of the interview data the survey questions were formulated and two survey instruments were designed, one for patients and one for family members. The items on the survey elicited information regarding perspectives concerning diagnosis, treatment, precautions, problems experienced, assistance received and selected demographics. In designing the actual survey questions, the format was based on patient questionnaires used with success in the past (Gray et al, 1997b, Fitch et al, 1999). Response options were designed to reflect a wide range of possible answers and were phrased using patient words derived from the preliminary interviews. A Likert type format was used as often as possible (Streiner & Norman, 1989). Additionally, opportunities were provided in many instances for participants to write a response to questions. A pilot test of the instrument was conducted by distributing the tool to individuals who had received I^{131} treatment. The feedback from these individuals validated the content and assured clarity and readability of the instruments (see appendices A & B for a copy of the survey instruments).

2.3 *Accrual*

A total of 700 patient surveys and 700 family member surveys were distributed to physicians at 8 sites across Canada. Location of sites were: Newfoundland, Nova Scotia, Ontario (2 sites), Quebec (2 sites), Manitoba, and British Columbia. Ethics approval for the project was obtained from all sites. Upon receipt of the surveys, each physician was asked to identify 35 patients with a malignant diagnosis and 35 patients with a non-

malignant diagnosis who had received I^{131} treatment, sometime within the previous two years. Patients from both urban and rural settings were included. Once the patients had been identified the physician mailed each patient a survey package. To ensure patient confidentiality the names of the patients were never shared with the researchers. Each survey package contained copies of the patient survey and the family member survey, a cover letter explaining the study (see Appendix C) and asking the patient to give the family survey to a family member who was living with them at the time of the I^{131} treatment, and pre-addressed, stamped return envelopes for each survey. The surveys were returned to the research office. Reminder notices were not sent as a part of the study. One hundred and ninety patients (response rate of 27%) and 140 family members (response rate of 20%) returned the survey.

2.4 Analysis of Data

Data from the patients and the family members were analysed separately. In both cases, data were divided in two groups: one for patients treated as an inpatient and one for patients treated as an outpatient. Analysis was descriptive and focused on means, medians and frequencies for single items as well as cross tabulations for a number of theoretically related variables. Selected tests of significance (t-test, median test, chi-square) were conducted, with a required significance level of $p < 0.01$ to account for multiple testing. Open-ended items were reviewed and subjected to a standard content analysis. Examples of the open ended comments will be reported to illustrated specific points.

3. Results

The results for this study will be presented in two sections. The first section will present the findings from the 190 individuals who received radioactive iodine therapy. The data will be presented according to the setting in which the treatment was received. The second section will present the results concerning the 130 family members who indicated the patient in their family had been treated as an inpatient or an outpatient. The data in this section will be reported according to whether the patient received the treatment in an inpatient or an outpatient setting.

4. SECTION ONE: PATIENT PERSPECTIVES

4.1 Demographic Characteristics

Table 1 presents the demographic information for the patients who responded to the survey. Overall, the patients had an average age of 48.7 years with a range of 12 to 84 years. Almost three-quarters (69.4%) of the respondents were female and 85% were Caucasian. Two-thirds (66.8%) were married or living with a partner. The majority (87.5%) had completed high school while almost half (47.1%) had also completed community college or university. Approximately one third (31.1%) had an income between $30,000 and $59,999. Almost a third (28%) lived in small communities of less than 5000 and 20.7% lived in communities with populations between 5000 and 49,999. Responses were received from each of the 6 provinces where surveys were distributed. The largest portion of responses (33.2%) was from Ontario where there were two distribution sites.

The inpatient and outpatient groups did not differ significantly in terms of the demographic characteristics (see Table 1).

4.2 Living Arrangements

The majority of both inpatient and outpatient respondents were living with an adult partner at the time they received their radioactive iodine therapy (see Table 2). Many (43% and 39%) were also living with children, of whom half were under the age of 12 years. Following their treatment with radioactive iodine therapy, the majority of respondents in both groups (84% and 78%) travelled home by private methods. Slightly more than a third (40% and 42%) spent more than an hour going home following their therapy. Of these groups, 3 patients travelled with children under 12 years of age. Almost half (55% and 40%) travelled with their spouse.

Of interest, over half of the patients in both groups (61% and 52%) had two or more bathrooms at home. Seventy percent in each group had a spare bedroom.

Table 1. Selected Patient Demographics

Characteristics	Inpatients (n=100)	Outpatients (n=90)	Total (n=190)
Age (average in years)	50.9	45.5	
(range in years)	14–84	12–77	
Gender			
Male	26.0%	25.6%	25.4%
Female	66.0%	72.2%	69.4%
Culture			
Caucasian	85.0%	84.4%	85.0%
Other	14.0%	14.4%	14.0%
Marital Status			
Married/Common law	71.0%	63.3%	66.8%
Never married/separated/divorced/ widowed	29.0%	36.7%	32.6%
Highest Education Level			
No formal	0%	3.3%	1.6%
Primary	9.0%	10.0%	9.3%
Secondary	35.0%	45.6%	40.4%
College/University	54.0%	40.0%	47.1%
Work			
Caring for family	21.0%	20.0%	20.2%
Work (paid or volunteer)	46.0%	51.1%	47.7%
Looking for work	0%	5.6%	2.6%
Retired	24.0%	18.9%	21.2%
Going to school	10.0%	7.8%	8.8%
Unable to do my normal activity	12.0%	8.9%	10.4%
Other	1.0%	1.1%	1.0%
Income Level			
Less than $10,000	2.0%	11.1%	6.7%
10,000 – 29,999	22.0%	16.7%	19.7%
30,000–59,999	34.0%	27.7%	31.1%
60,000–99,999	17.0%	9.3%	18.1%
>100,000	11.0%	4.4%	7.8%
Don't know	8.0%	11.1%	9.3%
Community Population			
Less than 5000	25.0%	31.1%	28.0%
5000–49,999	21.0%	21.1%	20.7%
50,000–249,999	15.0%	5.6%	11.4%
250,000–999,999	15.0%	16.7%	15.5%
1 million or more	17.0%	17.8%	17.1%
Province			
BC	18.0%	11.1%	15.0%
AB	0%	1.1%	0.5%
MN	8.0%	13.3%	10.4%
ON	36.0%	31.1%	33.2%
QUE	15.0%	14.4%	14.5%
NS	11.0%	16.7%	14.0%
NFLD	10.0%	12.2%	11.4%

Table 2. Patients' Living Arrangements At Time of Radioactive Iodine Treatment

Item	Percentage of Patients	
	Inpatients (n=100)	Outpatients (n=90)
Who was living with patient at time of therapy:		
No one	9.0	13.3
Adults	84.0	80.0
Children	43.0	38.8
Other	8.0	7.7
Children		
Under 12 years	48.0	50.0
Method of travel post treatment		
Private	84.0	77.8
Public	11.0	18.9
Length of travel time between home and hospital		
less than 1 hour	58.0	55.6
1–2 hours	20.0	23.3
more than 2 hours	20.0	18.9
Travel companion post treatment		
No one	20.0	43.3
Spouse/Partner	51.0	31.1
Children under 12 years	4.0	3.3
Children over 12 years	80.0	8.89
Other (other family, non-family, other)	22.0	27.8
Number of bathrooms in house		
1	36.0	47.8
2	40.0	41.1
>2	21.0	11.1
Spare bedroom in house		
Yes	69.0	70.0
No	28.0	28.9

4.3 Diagnosis and Treatment

The majority (64%) of the inpatient group had been diagnosed with malignant disease (see Table 3). Half (48%) of the respondents had received their diagnosis within the year prior to completing the survey while 30% had learned of their diagnosis between two and three years ago. On average they were 48.8 years old at diagnosis. The first changes they noticed that led them to think there was something wrong included: painless lump (53%), fatigue (38%), racing heart (21%) and weakness (20%). Half (50%) of the respondents indicated they were the first ones to have identified the change while 32% indicated it was their family doctor. The first test that resulted in an abnormal finding and suspicion of a thyroid condition was reported as physical examination (42%), biopsy (31%), ultrasound (20%) and blood test TSH (12%). Respondents indicated that they were informed of their condition by the following physicians: general surgeon (32%), family physician (23%), endocrinologist (20%) and oncologist (10%). When asked which other physicians they considered part of their treatment team, they indicated family physician (55%), nuclear medicine physician (48%), endocrinologist (38%), general surgeon (34%), and oncologist (28%).

The majority of the inpatient respondents had undergone a total thyroidectomy in addition to their radioactive iodine therapy and 92% reported they were currently on medication. Slightly more than half (57%) had had one radioactive iodine treatment while the remainder had had two or more. Forty-one percent indicated they had had to be off their medication for five to six weeks prior to their radioactive iodine treatment (see Table 4).

Table 3. Diagnosis Characteristics

Characteristics	Percentage of Patients	
	Inpatients (n=100)	Outpatients (n=90)
Diagnosis		
Malignant	64.0	44.4
Non-malignant	12.0	80.0
Growth – Unspecified	12.0	3.3
Uncertain of Diagnosis	8.0	6.6
No response	4.0	5.5
Time Since Diagnosis		
0–1 year	48.0	44.4
2–3 years	30.0	35.6
4–5 years	8.0	12.2
>5 years	12.0	5.6
Age at Diagnosis		
Average in years	48.8	42.2
Range in years	12–80 years	9–77
Time between first seeking medical help and diagnosis		
<1 month	36.0	61.1
1–3 months	32.0	24.4
4–12 months	15.0	4.4
>12 months	16.0	8.9
First changes noted by patient		
Painless lump	53.0	17.8
Fatigue	38.0	52.2
Racing heart	21.0	66.7
Weakness	20.0	44.4
Hoarseness	15.0	12.2
Tremors	13.0	54.4
Neck tightness/fullness	12.0	22.2
High blood pressure	10.0	20.0
Other	27.0	50.0
None	10.0	4.44

The majority (80%) of the outpatient group had been diagnosed with non-malignant disease (see Table 3). Almost half (46%) of the respondents had received their diagnosis within the year prior to responding to the survey while 36% learned of their disease between two and three years ago. On average they were 42 years old at diagnosis. The first changes they noticed that led them to think there was something wrong included: racing heart (67%), tremors (54%), fatigue (52%) and weakness (44%). Approximately half (47%) indicated their family doctor first identified the change while 38% indicated they had first identified the change themselves. The first test that resulted in an abnormal finding and suspicion of a thyroid condition was reported as blood test TSH (64%) and physical examination (23%). Respondents indicated that they were informed about their condition by the following physicians: family physician (66%) and endocrinologist (21%). When asked which other physicians they considered part of their treatment team, they indicated endocrinologist (54%), family doctor (53%) and nuclear medicine physician (32%).

The majority (68%) of the outpatients indicated they had received medication therapy in addition to their radioactive iodine treatment. Currently 60% indicated they were on medications. A majority (80%) had undergone a single radioactive iodine therapy treatment. Prior to this treatment, half (51%) of the respondents reported they had to be off their medications for up to two weeks.

Table 4. Treatment Characteristics

Characteristics	Percentage of Patients	
	Inpatients (n=100)	Outpatients (n=90)
Treatment received		
Partial thyroidectomy	18.0	2.2
Total thyroidectomy	85.0	7.8
Radioactive iodine	100.0	100.0
External radiation	11.0	1.11
Medication	65.0	67.8
Currently on Medication	92.0	60.0
Number of Radioactive Iodine Treatments		
One	57.0	80
Two	34.0	14.4
Three or more	9.0	5.6
Length of time off medication prior to radioactive iodine treatment		
0–2 weeks	16.0	51.1
3–4 weeks	10.0	5.6
5–6 weeks	41.0	5.6
>6 weeks	8.0	11.1

4.4 Communication and Access to Information

The majority of both inpatient (78%) and outpatient (86%) respondents indicated they had had someone with whom to talk about the diagnosis and treatment during the six weeks following their diagnosis (see Table 5). Inpatient respondents listed a variety of health care professionals with whom they could talk including family doctor (55%), general surgeon (52%), endocrinologist (25%), oncologist (21%), nuclear medicine physician (19%) and nurse (11%). The outpatient respondents indicated they could talk with the family doctor (74%), endocrinologist (57%) and nuclear medicine physician (20%).

A majority of both groups indicated they had received clear explanations about the treatment (84% and 79%) and side effects (74% and 70%) (see Table 5). Overall, patients who had had contact with the various health care professionals, reported relatively high levels of satisfaction with the communication styles to which they were exposed (see Table

6). On a 5-point Likert type response scale, mean satisfaction scores ranged from 3.9 to 4.5 for inpatients and 3.3 to 4.3 for outpatients. Some of the individuals who experienced communication difficulties wrote comments such as the following:

> *"I would like to recommend a well established communication process between doctor and patient, in particular to medications needed prior to going home from the hospital. I experienced lots of side effects/difficulties for not taking my thyroid medication until my next appointment to my doctor."*

Table 5. Patient Communication with Health Care Providers

	Percentage of Patients	
	Inpatients (n=100)	**Outpatients (n=90)**
First 6 weeks following diagnosis patient had doctor/nurse with whom they could openly discuss:		
Diagnosis	78.0	85.6
Treatment	71.0	72.2
Patient received clear explanation of:		
Treatment	84.0	78.9
Side Effects	74.0	70.0
Patient experienced difficulty talking with health care providers	11.0	8.9
Patient experienced difficulty understanding or selecting treatment options	7.0	12.2

Table 6. Percentage of Patients Who Reported Satisfaction with Communication with Health Care Professionals

	Percentage of Respondents Satisfied*			
	Inpatient (n=100)		Outpatients (n=90)	
Precautions	Rated 4 or 5*	No response and N/A	Rated 4 or 5*	No response and N/A
Family Physician	58.0	15.0	74.4	12.2
Endocrinologist	39.0	51.0	55.6	31.1
General Surgeon	66.0	21.0	11.1	77.0
Nuclear Medicine Physician	70.0	20.0	51.1	37.8
Oncologist	39.0	55.0	4.44	93.3
Nurse	58.0	32.0	17.8	73.3
Nuclear Medicine Technician	71.0	16.0	54.4	32.2
Physicist	6.0	93.0	2.22	95.6

* Respondents indicating 4 or 5 on a scale where 1 = extremely dissatisfied and 5 = completely satisfied

The importance of various types of information was assessed using a 5-point Likert scale. The majority of respondents in both groups rated information about their medical condition, tests and procedures, treatment choices and side effects of treatment as very important (see Tables 7 and 8). Topics such as preparing one's home for after treatment, how to relieve physical discomfort, preparing for hospitalization, and diet and nutrition, and emotional side effects were also considered very important by more than two-thirds of the respondents. Across all topics, no more than 72% of the respondents indicated feeling satisfied with the information they had received. The topics for which the lowest proportions of respondents indicated satisfaction were how to arrange to speak with another patient in the same situation, availability of counselling services, emotional effects, and diet and nutrition.

Comments written by patients reinforced the value of information:

> *"Although my doctor explained to me what I was to expect regarding receiving radioactive iodine, I would have appreciated some written information prior to going to hospital around what to expect. It would have been nice to talk to someone who had received radioactive iodine in order to hear what that person's experience was as well as to normalize this whole experience for me."*

Table 7. Information Inpatients Reported as Important During Radioactive Iodine Treatment

Topic	Percentage of inpatients indicating the topic was important *	Percentage of inpatients who were satisfied with the information received**
Medical condition	92.0	65.0
Planning for tests and procedures	87.0	72.0
Treatment choices available	88.0	62.0
Possible side effects of treatment	88.0	55.0
Possible emotional effects	67.0	43.0
What to do to relieve physical discomfort	69.0	60.0
Diet and nutrition	63.0	45.0
Counselling services available	42.0	30.0
How to arrange to speak with another person with the same condition	49.0	28.0
Preparing for hospitalization	67.0	67.0
Preparing your home after treatment	71.0	61.0

* Respondents indicating 4 or 5 on a scale where 1 = not at all and 5 = extremely important.

** Respondents indicating YES on a dichotomous item.

Table 8. Information Outpatients Reported as Important During Radioactive Iodine Treatment

Topic	Percentage of outpatients indicating the topic was important*	Percentage of outpatients who were satisfied with the information received**
Medical condition	92.2	68.9
Planning for tests and procedures	83.3	71.1
Treatment choices available	91.1	72.2
Possible side effects of treatment	88.9	62.2
Possible emotional effects	73.3	53.3
What to do to relieve physical discomfort	70.0	53.3
Diet and nutrition	71.1	44.4
Counselling services available	44.4	30.0
How to arrange to speak with another person with the same condition	41.1	33.3
Preparing for hospitalization	31.1	34.4
Preparing your home after treatment	54.4	53.3

* Respondents indicating 4 or 5 on a scale where 1 = not at all and 5 = extremely important.

** Respondents indicating YES on a dichotomous item.

"Pretreatment information package to include possible side effects of being off your thyroid medication. Information on how to get help if you need it while you are feeling so low, for low thyroid levels. Explain that it would take several months after treatment to get thyroid levels up. Therefore need to take time off work and get help."

"No problems with the abilities or explanations (verbal) of the treatment but would, in retrospect, have liked more literature on the diagnosis and the options for treatment – between learning it and discussing it – but before taking it."

"I found it frustrating that treatment took 10 months to get to where I am today. I also would have liked more information (e.g., diet and nutrition) and more information on choices of treatment. However, I am feeling better now but would like to know what to expect in the future."

4.5 Experiences Receiving Radioactive Iodine Treatment

The respondents who received their therapy on an inpatient basis and received higher doses of I^{131}, reported more symptoms (see Table 9) than the respondents who received their treatment as an outpatient (see Table 10). For the inpatient group the most frequently identified symptoms were fatigue (63%), dry mouth (52%), and feeling down or depressed (51%). The outpatients reported fatigue (56%) and anxiety (52%) most frequently.

When asked whether or not they had received adequate assistance for the problems they had experienced, few inpatient and outpatient respondents reported receiving adequate help (see Tables 9 and 10). For example, 18% of the inpatient respondents who experienced fatigue reported receiving adequate assistance regarding this issue and 12% of the outpatients did so. For the inpatients who experienced a dry mouth, 15% of the inpatients and 17% of the outpatients reported receiving adequate assistance with this problem. This same pattern was observed across most problems patients experienced.

Table 9. Proportion of Inpatients Who Experienced Symptoms/Difficulties

Symptom	Percentage of Inpatients	
	Experienced Symptoms/Difficulties (n=100)	Reported Receiving Adequate Help for Symptoms/Difficulties*
Fatigue	63.0	17.5
Dry mouth	52.0	15.4
Feeling down or depressed	51.0	13.7
Feeling isolated	48.0	37.5
Anxiety	47.0	21.3
Difficulty concentrating	43.0	25.6
Appetite changes	40.0	27.5
Difficulty with child care	40.0	20.0
Muscle cramps	40.0	15.0
Nausea	37.0	100.0
Difficulty with household responsibilities	37.0	51.4
Fear	37.0	40.5
Change in how you feel about your body	36.0	8.3

* Denominator used in each case was the number of patients who experienced the symptom/difficulty.

Table 10. Proportion of Outpatients Who Experienced Symptoms/Difficulties

Symptom	Percentage of Respondents	
	Experienced Symptoms/Difficulties (n=90)	Reported Receiving Adequate Help for Symptoms/Difficulties*
Fatigue	55.6	12.0
Anxiety	52.2	17.0
Feeling down or depressed	44.4	12.5
Dry mouth	40.0	8.3
Difficulty concentrating	40.0	16.7
Difficulty sleeping	38.9	45.7
Appetite changes	38.9	14.3

* Denominator used in each case was the number of patients who experienced the symptom/difficulty

All but one of the inpatients were isolated during their hospitalization for treatment. Approximately three-quarters (73%) were isolated for 2 to 3 days while 16% were isolated for longer than 3 days. When asked about the amount of physical contact with nursing staff during that period, 29% indicated there was no contact with nursing staff, 18% indicated contact once a day, and 32% indicated contact 2 to 3 times a day. Of the 18% who had one contact per day, that contact was reported to be less than one minute in 56% of the cases. In terms of telephone contact, 57% of the inpatients reported no contact with the nurse, 15% reported one telephone contact and 21% reported 2 to 3 telephone contacts per day with the nurse. When asked about the adequacy of the contact with the nursing for meeting the needs the patient experienced, 77% indicated the contact was enough. Comments from the patients who experienced difficulties with isolation reflected the following:

> *"The part of the hospital stay that made things so difficult was the isolation in the room. The nurses for the most part were inexperienced and obviously hesitant to be exposed to me. I was very unwell the first night of my treatment (nausea and vomiting) and felt very alone...I wish I had received some extra emotional support, if not only talking to me through the intercom."*

> *" Should be a T.V. in room that works and is turned on. I was upset because they would not turn T.V. on or take my money. Appreciated phone...was not given any information ahead of time that I would be in isolation. Shower would be nice."*

> *"I have had three treatments. My biggest complaint is no shower and cold meals. I recommend: 1) have a shower available, 2) bigger room to do exercises, etc., 3) have a real T.V. – 20" with some tapes and VCR, 4) let the nurses know they won't die by opening the door and talking to you for a few minutes, 5) kitchen help would leave food outside door. I would wait in sometimes 30 to 45 minutes for it...Treatment and physical health were fine. Being treated like BLACK DEATH got on my nerves..."*

Finally, inpatients were asked what made the interval in hospital easier. The following suggestions were made: television and telephone in the room (80%), window in the room (70%), nurse (39%), physician (27%), technician (22%), reading/school work (22%) and visitors (19%). Comments written by patients also reflected the desire for more information about the time in the hospital. For example,

> *"A printed copy of instructions when receiving the radioactive iodine in the hospital, rather than just an oral explanation of all the DOs and DON'Ts."*

4.6 Precautions

Patients who received their treatment on an inpatient basis were asked what precautions were put in place during that time. Table 11 presents their responses. The most frequently identified precautions were that the radioactive iodine was in a special container (98%), the patient drank lots of fluids (94%), the patient flushed the toilet twice (93%), and others kept their distance from the patient (91%). The precautions identified by the lowest proportion of patients included visitors staying a short time (25%), and the patient showering frequently (28%).

Table 11. Precautions Used During Inpatient Radioactive Iodine Treatment

Precaution	Percentage of Inpatients (n=100)
Radioactive iodine was in a special container	98.0
Patient drank lots of fluids	94.0
Flush toilet twice	93.0
Others kept their distance	91.0
Patient washed hands thoroughly	88.0
Laundry kept in room	85.0
Dishes left in room	82.0
Technician wore gloves	79.0
Radioactivity measured daily	77.0
Not able to have visitors	61.0
Patient sucked on candy/lemons	57.0
Patient showered frequently	28.0
Visitors stayed short time	25.0

All respondents were asked what precautions were put in place in the home environment following the administration of the radioactive iodine therapy. For the inpatients who had been discharged home, the precautions identified by the largest number of patients included washing hands thoroughly (91%), drinking lots of fluids (86%) and flushing the toilet twice (84%). For the outpatients, the most frequently identified precautions included washing hands thoroughly (82%), flushing the toilet twice (79%) and avoiding contact with children and women who are pregnant (71%). Overall, more respondents in the inpatient group indicated precautions were in place at home than did the outpatient group (see Table 12).

Table 12. Precautions Taken at Home Following Radioactive Iodine Treatment

Precaution	Percentage of Patients	
	Received Treatment as an Inpatient	Received Treatment as an Outpatient
Washing hands thoroughly	91.0	82.2
Drinking lots of fluid	86.0	54.4
Flushing toilet twice	84.0	78.9
Avoiding contact with children/ pregnant women	77.0	71.1
Sleeping alone	72.0	54.4
Avoid kissing/hugging	70.0	57.8
Keeping distance from family	59.0	45.6
Showering frequently	57.0	36.7
Keeping distance from others	50.0	51.1
Using own utensils or plastic utensils	50.0	51.1
Staying by self in separate room	44.0	23.3
Washing clothes/linen separately	43.0	26.7
Stop breast feeding	4.0	1.1
Other	6.0	7.7
Didn't know I needed precaution	0.0	3.3

When asked which precautions were difficult for the inpatients, the largest number of patients identified being unable to do the things the patient usually does (42%), being off the thyroid medication prior to treatment (41%), being unable to get too close to children or family (39%), being isolated (27%) and being unable to have visitors (27%) (see Table 13). The outpatient respondents indicated the difficult precautions for them included being unable to get too close to family members or children (29%) and being unable to do the things the patient normally does (24%).

Table 13. Patients Reporting Difficulty Regarding Precautions

Precautions	Percentage of Respondents Reporting Difficulty*			
	Inpatient (n=100)		Outpatients (n=90)	
	Rated 4 or 5*	Not Applicable	Rated 4 or 5*	Not Applicable
Being isolated/staying alone	27.0	3.0	13.3	35.6
Being in hospital	20.0	5.0	-	-
Being unable to get too close to children/family members	39.0	7.0	28.9	23.3
Being off my thyroid medication before treatment	41.0	19.0	15.6	77.8
Being unable to have visitors	27.0	13.0	12.2	47.8
Having to store food in hospital room	12.0	6.0	-	-
Drinking lots of fluids	8.0	4.0	2.2	24.4
Being unable to do things I normally do	42.0	6.0	24.4	32.2
Sleeping alone	10.0	7.0	11.1	37.8

* Respondents indicating 4 or 5 on a scale where 1 = not at all difficult and 5 = extremely difficult

Respondents indicated they did have concerns about the radioactive iodine therapy when they were at home. Both inpatients and outpatients identified their own concerns as worry that others would receive a dose of radiation from them, worry about what the radiation would do to the rest of their bodies, and concerns about whether the radiation is gone (see Table 14). Their perception of their family member's concerns are listed in Table 15. In both groups most patients thought their family members worried about whether the treatment was successful and whether or not the radiation was gone. The following comment illustrates the concerns patients experienced:

> *"I keep wondering if it's so dangerous, how can it be safe to give to us. It doesn't kill the ones who receive it, so it makes me wonder if it is as bad as some people think. I find that my father gets worried. He wonders how it will affect the rest of my body, when its strong enough to kill the cancer..."*

Table 14. Patients' Concerns About the Home Environment Following Treatment with Radioactive Iodine

Concerns	Percentage of Respondents	
	Received Treatment as an Inpatient	Received Treatment as an Outpatient
Whether others would receive a dose of radioactive iodine from me.	53.0	42.2
What radioactive iodine might do to the rest of my body.	52.0	62.2
Whether the radioactivity is gone.	50.0	43.3
How to keep isolated from others	35.0	20.0
No concerns	21.0	20.0
Other	3.0	4.4

Table 15. Patients' Perception of Family's Concerns When Returning Home After Treatment with Radioactive Iodine

Concerns	Percentage of Patients	
	Received Treatment as an Inpatient	Received Treatment as an Outpatient
Wondering if the treatment worked	57.0	57.8
Wondering whether the radioactivity was gone	47.0	40.0
Possibility of being contaminated	37.0	28.9
Thinking about how to keep away from the patient	21.0	12.2
No concerns	18.0	21.1
Other	10.0	1.1

The individuals who received their treatment as an inpatient were specifically asked if they would consider receiving radioactive iodine therapy on an outpatient basis should they require another treatment. More than half (58%) indicated they would not consider having future radioactive iodine treatments on an outpatient basis while 22% were uncertain if they would. The concerns they identified included wondering whether other people would receive a dose of radiation from them (81%), wondering how the patient could know that the radiation was gone (73%), wondering if the radiation would contaminate the house (71%) and feeling that they would need more information to receive the treatment as an outpatient (59%).

4.7 Impact of the Illness and Treatment

Respondents were asked to rate their quality of life, on a 7-point Likert type scale, before and after their treatment with radioactive iodine therapy. The average score before treatment for the inpatient group was 5.3 and after treatment was 5.1. The average score before treatment for the outpatient group was 5.2 and after treatment was 5.3. There were no statistically significant differences observed between the mean scores for either group. The types of comments patients wrote about the impact on quality of life are illustrated below:

> *"Having cancer is not easy! When you hear the word your life changes. I read and think more about my health and energy level. Taking medication for my life was not easy. I am not a pill taker. Going off synthyroid for treatment and test is very hard on fatigue, energy, mental health. I have a more positive attitude but I am not able or have not as yet resumed my prior very active lifestyle (golf, walk, etc.). I do appreciate life and small things more. It has been hard coming and going from my job – stressful since I want to do a good job and work is important to my well-being."*

> *"From diagnosis to treatment it affected my life – ups and downs of treatment, plus my own attempts at self-monitoring. After iodine and thyroid replacement things are relatively usual. The main difference is my own perception of my health and a sense my body is failing me."*

> *"I can finally lead a normal life again without always being tired and moody. I also can finally enjoy my grandson again."*

> *"Trouble keeping weight down. Less tolerance for exercise. No social life because of fatigue and depression."*

Respondents were also asked to indicate the degree of impact their illness and treatment had had for them. For the inpatient group, 53% indicated they had experienced a lifestyle change while 20% of the outpatient group experienced a lifestyle change (χ^2=19.8, p<0.001). The lifestyle changes patients wrote about are illustrated in the following quotes:

> *"Lack energy. Lost interest in daily activities and in social activities. Lack concentration. Don't want to get out of bed."*
>
> *"I enjoy life more, don't take things for granted or let things upset me. I have the meaning of life."*
>
> *"Work less, enjoy life more, more rest, more pleasure, vitamins."*
>
> *"You are always taking medications, follow-up appointments and wondering if its going to come back."*

As far as actual impact, relatively few respondents indicated a negative impact from the disease or treatment (see Table 16). The proportions of inpatient respondents who experienced a negative impact was largest for the domains of mental health (36%) and household responsibilities (34%). In the outpatient group the largest proportion who experienced a negative impact, was the domain of mental health (23%). Comments patients wrote regarding negative impact are like the following:

> *"Unable to deal with disease and long term (life) therapy requirements. Depressed about weight gain/energy loss."*
>
> *"I was unable to work due to my condition and this has happened to me three times. Financially this has a huge impact. I am still not recovered from the radiation therapy which I finished 7 weeks ago."*
>
> *"Has initially made me more aware of changes in my body and the need to be more alert. The diagnosis of `cancer' itself is terrifying and it's hard to stop worrying that it will come back. Makes you appreciate what you have in life and how lucky you are."*
>
> *"I now fear every lump and bump I find on my body. I also fear that the cancer will come back again. I worry that I will pass on the genetic disposition to my children."*

Table 16. Patients' Report Regarding Impact of Radioactive Iodine Treatment on Lifestyle

Items	Percentage of Inpatients (n=100)		Percentage of Outpatients (n=90)	
	Negative Impact 1 or 2*	Not applicable	Negative Impact 1 or 2*	Not applicable
Relationship with Partner	10.0	19.0	11.1	23.3
Relationship with Children	7.0	19.0	10.0	25.6
Relationship with Friends	9.0	3.0	7.8	7.8
Employment opportunities	18.0	30.0	10.0	27.8
Work life (paid or volunteer)	27.0	32.0	12.2	25.6
Financial status	25.0	22.0	15.6	20.0
Leisure or retirement time	23.0	10.0	13.3	13.3
Mental health	36.0	7.0	23.3	3.3
Household responsibilities	34.0	4.0	2.0	5.6

* Respondents indicating 1 or 2 on a scale where 1 = negative impact and 5 = positive impact

4.8 Support

Somewhat more than half of both inpatient (64%) and outpatient (54%) respondents indicated they had felt the need to talk with someone about issues concerning their thyroid condition and treatment. Of these individuals 80% of the inpatients and 81% of the outpatients had someone with whom they could talk. The inpatients most frequently identified physician (65%), other patient (31%) and partner (19%) as the individual with whom they could talk. The outpatients identified physicians (80%), and partners (15%) most frequently.

Eleven percent of the inpatient group and 5.6% of the outpatient group saw a professional counsellor about issues related to the thyroid condition or treatment. Of those who did not see a counsellor, 20% of the inpatients and 14% of the outpatients would have like to have seen someone.

Only 2% of inpatients and 5.6% of outpatients attended a support or educational group for thyroid conditions. Of those who did not participate in such a session, 24% of the inpatients and 27% of the outpatients would like to have participated in one.

During their treatment relatively few inpatient or outpatient respondents received information and/or help from formal organizations. The inpatient groups reported receiving help most frequently from the Thyroid Foundation of Canada (8%) and the Canadian Cancer Society (4%) while the outpatient group received help from the Thyroid Foundation of Canada (8%). Respondents who received help from these agencies shared the following comments:

> *"My greatest help has come from [name] from the Cancer Connection – a wonderful telephone service with which my daughter put me in touch."*

> *"Any information would have been helpful, even knowing there was a Thyroid Foundation or that what I was feeling was normal. There should be an automatic handout from the Thyroid Foundation for people who are diagnosed with thyroidism."*

For the most part, patients found individuals were helpful to them (see Table 17). Doctors were cited most frequently as being very helpful by both inpatients (78%) and outpatients (71%). Spouses, other family members and friends were cited most frequently following physicians in both groups.

Table 17. Sources Patients Identified as Helpful Since Diagnosis

Sources of Help	Percent of Patients			
	Inpatient (n=100)		Outpatients (n=90)	
	Rated 4 or 5*	Not Applicable	Rated 4 or 5*	Not Applicable
Partner/Spouse	66.0	17.0	57.8	25.6
Other family	71.0	6.0	57.8	17.8
Children	53.0	24.0	36.7	34.4
Friends	66.0	6.0.0	50.0	14.4
Nurses	51.0	14.0	30.0	42.2
Doctors	78.0	1.0	71.1	5.6
Self-help groups	2.0	67.0	4.4	76.7
Other patients	10.0	53.0	7.8	72.2
Clergy/Counsellors	13.0	56.0	3.3	80.0
Nuclear Medicine Technician	43.0	9.0	44.4	21.1
Canadian Cancer Society	27.0	40.0	4.4	78.9
Literature	36.0	19.0	35.6	32.2
Media (Magazine, TV)	14.0	37.0	17.8	51.1
Thyroid Association	10.0	52.0	8.9	64.4

* Respondents indicating 4 or 5 on a scale where 1 = not at all helpful and 5 = extremely helpful.

5. SECTION TWO: FAMILY MEMBER RESULTS

5.1 Demographic Characteristics

Table 18 presents the demographic information regarding the family members who responded to the survey. The average age of the family respondents was 46.3 years with a range of 10 to 82. Half of the respondents (51%) were female and 83% were Caucasian. Almost two-thirds (62%) were partners (spouses) to the patients participating in the study. Slightly more than half (57%) were working and 14% were retired. The majority had completed secondary school (92%) while half (50%) had also completed community college or university. The largest proportion of respondents had household incomes in $30,000 to $59,999 range (34%). The respondents were well distributed over communities ranging from less than 5000 (22%) and 5000-49,000 (28%) to 50,000-249,999 (28%). Responses were received from each of the 6 provinces where distributions sites were located. The largest proportions were received from Ontario (30%) and British Columbia (16%).

Sixty-eight of the family respondents had a patient treated in the inpatient setting and 62 had a patient treated as an outpatient. The two family member groups were similar in terms of demographic characteristics.

5.2 Diagnostic and Treatment

Of the family members who had had a patient treated as an inpatient, 66% of those patients reported malignant disease. Half of the inpatients (53%) had been diagnosed within the last year while 32% had received their diagnosis between two and three years ago. Of the family members who had had a patient treated as an outpatient, 86% had been diagnosed with non-malignant disease. Half of the outpatient group (50%) had received the diagnosis in the past year while 29% learned of their diagnosis two to three years ago.

Table 18. Selected Demographics – Family Member

Characteristics	Inpatients (n=68)	Outpatients (n=62)	Total (n=130)
Age (average in years)	47.1	45.5	
(range in years)	10–82	13–81	
Gender			
Male	42.6%	43.5%	40.7%
Female	51.5%	50.0%	51.4%
Culture			
Caucasian	82.4%	87.1%	82.9%
Other	16.2%	11.3%	14.3%
Relationship to patient			
Spouse/Partner	58.8%	69.4%	62.1%
Child	32.4%	19.4%	27.1%
Sibling	-	2.9%	1.4%
Other	11.3%	5.9%	7.9%
Work			
Caring for family	19.1%	21.0%	18.6%
Work (paid or volunteer)	58.8%	64.5%	57.1%
Looking for work	-	4.8%	2.1%
Retired	17.6%	12.9%	14.3%
Going to school	7.4%	3.2%	5.0%
Unable to do my normal activity	1.5%	1.6%	1.4%
Other	2.9%	1.6%	2.14%
Highest Education Level			
No formal	-	1.6%	0.7%
Primary	4.41%	3.2%	3.6%
Secondary	38.2%	46.8%	41.4%
College/University	55.9%	45.2%	50.7%
Total Household Income			
<10,000	1.5%	3.2%	2.1%
10,000–29,999	10.3%	16.1%	12.9%
30,000–59,999	41.2%	30.6%	34.3%
60,000–99,999	25.0%	27.4%	26.4%
100,000	5.9%	8.1%	6.4%
Don't know	8.82	4.84%	7.9%
Community Population			
Less than 5000	23.5%	22.6%	22.1%
5000–49,999	26.5%	32.3%	27.9%
50,000–249,999	22.1%	12.9%	27.9%
250,000–999,999	14.7%	9.7%	14.3%
1 million or more	10.3%	17.7%	12.9%
Province			
BC	20.6%	11.3%	15.7%
MN	10.3%	8.1%	10.7%
ON	30.9%	30.6%	30.0%
QUE	14.7%	16.1%	14.3%
NS	13.2%	17.7%	14.3%
NFLD	10.3%	14.5%	12.9%

The family members for the inpatient group reported that, in addition to the radioactive iodine treatment, 84% of the patients received a total thyroidectomy. Fifty-nine percent of these patients underwent a single radioactive iodine treatment. The family members of the outpatient group indicated 50% of the patients had received medication in addition to the radioactive iodine therapy. In this group of patients, 82% experienced a single radioactive iodine treatment.

5.3 Communication

In the six weeks following the patients' diagnosis of a thyroid condition, approximately half of the inpatient family members (54%) and slightly less than half of the outpatient family members (44%) felt they had someone with whom to talk about the diagnosis. Somewhat fewer felt they had someone with whom to talk about the treatment (see Table 19). The inpatient family members reported most frequently they could talk with the general surgeon (40%) and the family physician (34%). Twenty-one percent actually indicated there was no one with whom they could talk. The outpatient family members reported they could talk with family doctors (42%) and endocrinologists (24%). Twenty-seven percent indicated they did not have anyone with whom they could talk.

Approximately two-thirds of the inpatient family members (62%) and half of the outpatient family members (53%) felt they had received a clear explanation of how radioactive iodine treatment works. Approximately 20% in both groups reported difficulty understanding treatment options and talking with health care professionals. The following comments reflect some of the difficulties:

> *"For such a critical illness/surgery, medical personnel should take more time and make more effort to ensure the patient and their spouse/partner are better informed about the illness, the treatment, the after-effects, etc. We felt very "under-informed". Medical personnel may be always busy but they need (for the most part) to take more time with patients who have critical surgery such as thyroid cancer."*
>
> *"Not enough information received about risks and side effects of radioactive therapy."*
>
> *"...I believe that any patient should be encouraged to invite and have present another family member in discussion of diagnosis and treatment.*

It's always good to have a "three way" discussion to give voice to hearsay, concern, apprehension, to elicit subjective comments concerning the diagnosis or treatment. Most of us have access to libraries, but this does not lessen the need of and for readable pamphlet information on the particular illness or condition."

"The lack of information and support, other than from our local surgeon, was disgraceful. We felt alone and still do in our attempt to achieve the correct level of hormone treatment."

Table 19. Family Member Communication with Health Care Providers

Items	Percentage of Patients	
	Inpatient (n=68)	Outpatient (n=62)
First 6 weeks following patient's diagnosis family member had doctor/nurse with whom they could openly discuss:		
Diagnosis	54.4	43.5
Treatment options	48.5	35.5
Family member received a clear explanation of:		
How radioactive iodine treatment works	61.8	53.2
Side effects of radioactive iodine treatment	54.4	54.8
Family member experienced difficulty understanding treatment options	19.1	24.2
Family member experienced difficulty talking with health care providers	19.1	11.3

Overall, those who had had contact with various health care professionals, reported relatively high levels of satisfaction with the communication style to which they had been exposed (see Table 20). On a 5-point Likert type scale, the mean satisfaction scores for the inpatient family members ranged from 3.6 to 4.4 while those for the outpatient family members ranged from 3.3 to 4.2.

Table 20. Percentage of Family Members Who Report Satisfaction with Communication with Health Care Professionals

Precautions	Percentage of Respondents Satisfied*			
	Inpatient (n=68)		Outpatients (n=62)	
	Rated 4 or 5*	No response & N/A	Rated 4 or 5*	No response & N/A
Family Physician	45.6	33.8	40.3	40.3
Endocrinologist	29.4	58.8	33.9	54.8
General Surgeon	50.0	29.4	9.7	87.1
Nuclear Medicine Physician	38.2	58.8	37.1	54.8
Oncologist	26.5	66.2	4.8	93.5
Nurse	35.3	48.5	14.5	83.9
Nuclear Medicine Technician	32.4	58.8	38.7	53.2
Physicist	2.94	92.6	3.2	95.2

* Respondents indicating 4 or 5 on a scale when 1 = extremely dissatisfied and 5 = completely satisfied.

The majority of family members in both the inpatient (>77%) and outpatient groups (>83%) indicated information about the patients medical condition, tests and procedures, treatment choices and side effects was important for them as a family member to know (see Tables 21 and 22). In addition topics such as emotional effects, diet and nutrition, preparing for hospitalization and preparing the home for after treatment were cited as important for the family member to know by two-thirds of the respondents. Within both family member groups, no more than about half of the respondents indicated they were satisfied with the information they received across all topic areas with the exception of the outpatient group concerning three items: treatment options (61%), the patients' medical condition (57%) and tests and procedures (57%). The following comments reflect the difficulties some family members felt:

> *"People should be made more aware of what radioactive iodine treatment is. My spouse was sent home from outpatient treatment with very little information on what he should and shouldn't do. I have to admit I was very nervous being around him..."*

> *"I feel my husband's health was taken rather lightly. Just another illness. We were very misinformed. No support was offered and extreme lack of explanation. Luckily my husband has the initiative to get information off the Internet."*

> *"[we need] informational pamphlets for spouses/children; description of treatments with radioactive iodine; side effects; more open health care professionals."*

Table 21. Information Family Members Reported as Important with Inpatient Radioactive Iodine Treatment

Topic	Percentage of Respondents	
	Family Members of Patient Treated as an Inpatient indicating the topic was important* (n=68)	Family Members of Patients Who were Treated As an Inpatient who were satisfied with information received** (n=62)
Family member's medical condition	91.2	54.4
Planning for tests and procedures	77.9	52.9
Treatment choices available	80.9	50.0
Possible side effects of treatment	83.8	50.0
Possible emotional reactions	73.5	27.9
What to do to relieve physical discomfort	60.3	29.4
Diet and nutrition	67.6	29.4
Counselling services available	44.1	17.6
How to arrange to speak with another person with the same thyroid condition	42.6	16.2
Preparing for hospitalization	69.1	48.5
Preparing your home after treatment	64.7	38.2

* Respondents indicating 4 or 5 on a scale where 1 = not at all and 5 = extremely important.

** Respondents indicating YES on a dichotomous item.

Table 22. Information Family Members Reported as Important With Outpatient Radioactive Iodine Treatment

Topic	Percentage of Respondents	
	Family Members of Patients Treated as Outpatients indicating the topic was important* (n=68)	Family Members of Patients Treatment as Outpatients who were satisfied with information received**
Family member's medical condition	91.9	56.5
Planning for tests and procedures	83.9	56.4
Treatment choices available	90.3	61.3
Possible side effects of treatment	87.1	51.6
Possible emotional reactions	64.5	41.9
What to do to relieve physical discomfort	79.0	43.5
Diet and nutrition	62.9	41.9
Counselling services available	30.6	33.9
How to arrange to speak with another person with the same condition	35.5	29.0
Preparing for hospitalization	32.3	37.1
Preparing your home after treatment	53.2	43.5

* Respondents indicating 4 or 5 on a scale where 1 = not at all and 5 = extremely important.

** Respondents indicating YES on a dichotomous item.

5.4 Experiences During Radioactive Iodine Treatment

The family members who had a patient treated as an inpatient reported that 96% of the patients were isolated. About a third (34%) were isolated for 1 to 2 days and a half (53%) were isolated for 3 to 4 days. During the isolation, 63% of the patients were not allowed to have visitors and 25% were able to have limited visiting.

From the perspective of the family member, the items that made it easier for the family member during the isolation period included: knowing the isolation was only for a few days (69%), being able to phone the patient (68%), being able to have a short visit with the patient (25%) and the nurse (21%).

5.5 Precautions

Family members were asked to report on the precautions which were put in place upon the patients' return home. Table 23 provides a listing of the precautions the respondents

identified. The most frequently identified precautions for the group with an inpatient included flushing the toilet twice (75%), drinking lots of fluids (74%) and avoiding contact with children or pregnant women (72%). For the patients treated as an outpatient, the family members identified washing hands thoroughly (76%) and flushing the toilet twice (69%) most frequently.

Table 23. Precautions Patients Took at Home Following Radioactive Iodine Treatment as Reported by Family Member

Precaution	Percentage of Patients	
	Received Treatment as an Inpatient (n=68)	Received Treatment as an Outpatient (n=62)
Flushing toilet twice	75.0	69.4
Drinking lots of fluids	73.5	54.8
Avoiding contact with children/pregnant women	72.1	62.9
Washed hands thoroughly	66.2	75.8
Sleeping alone	61.8	48.4
Avoid kissing/hugging	60.3	62.9
Keep away from others	58.8	46.8
Wash clothing/linen separately	47.1	32.3
Use own utensils or plastic utensils	42.6	51.6
Stayed alone or apart from family	42.6	30.6
Showered frequently	41.2	30.6

The family members identified the aspects of the precautions with which they had difficulty (see Table 24). For the family members of inpatients, the largest proportion had difficulty with the patient being off thyroid medication before treatment (49%) and the patient being in hospital (47%). The family members of outpatients identified the patient being unable to get too close to the rest of the family and children (21%) as difficult.

Table 24. Family Members Reporting Difficulty Regarding Precautions Taken by Patients

Precautions	Percentage of Respondents Reporting Difficulty*			
	Inpatient (n=68)		Outpatients (n=62)	
	Rated 4 or 5*	Not Applicable	Rated 4 or 5*	Not Applicable
Patient being isolated	44.1	5.9	14.5	32.3
Patient being in hospital	47.1	1.5	-	-
Patient unable to get too close to children/family members	44.1	5.9	21.0	19.4
Patient being off thyroid medication before treatment	48.5	8.8	19.4	30.6

* Respondents indicating 4 or 5 on a scale where 1 = not at all difficult and 5 = extremely difficult

Family members were able to identify concerns they had about the patient being at home after the radioactive iodine treatment (see Table 25). The largest proportion of family members in both the inpatient and outpatient groups identified a concern about whether the treatment worked (82% and 76%). The next highest proportion concerned whether the radiation was gone from the home environment (54% and 45%). Some of the confusion is indicated in the following comments:

> *"When A. had radioactive iodine therapy he wasn't admitted to hospital. Some people have to be isolated. I was kind of concerned about that and it's nice to know the difference if you do or don't."*
>
> *"...my partner had two outpatient radioactive treatments and NO precautions were told to us."*
>
> *"As we were kept uninformed of precautions to be aware of we were not concerned about same. Perhaps no knowledge is needed."*

Family members with a patient who was treated as an inpatient were asked if radioactive iodine therapy could be given safely on an outpatient basis would they consider this option in the future. 29.4% indicated they would not consider outpatient delivery and 25% were uncertain. The concerns they identified included: wondering whether other people at home would receive a dose of radiation from the patient (55.9%), wondering

Table 25. Family Members' Concerns About the Home Environment Following Patients' Treatment with Radioactive Iodine

Concerns	Percentage of Respondents	
	Family Member of Patients' Treatment as an Inpatient (n=68)	Family Member of Patients' Treatment as an Outpatient (n=62)
Wondering if the treatment worked	82.4	75.8
Whether the radioactivity was gone	54.4	45.2
Wondering if other people could get a dose of radiation from the family member	36.8	45.2
How to keep far enough away from patient	33.8	19.4
Whether I would be contaminated	33.8	35.5
Wondering what the radioactivity might do to my body	27.9	27.4
No concern	7.4	9.7
Other	1.5	6.5

how to tell when the radioactivity was gone (54.4%), and wondering if the house would be contaminated (50%). More than half (63.2%) indicated they would need more information if the patient was treated on an out-patient basis.

5.6 Impact of the Disease on the Family Member

The family members experienced a range of issues themselves during the interval of the radioactive iodine treatment (see Table 26 and 27). Anxiety was identified by more than half of the family members in the inpatient (62%) and the outpatient (52%) groups. Both groups identified the same types of issues including feeling apart from the patient, fear, and feeling down or depressed. When asked whether or not they had received adequate assistance for the problems they had experienced, there was considerable variation in the numbers of individuals who felt they had received adequate help (see Table 26, 27).

Table 26. Symptoms/Difficulties Experienced by Family Members of Individuals Treated on an Inpatient Basis

Symptom	Percentage of Respondents	
	Family Members Who Experienced Symptoms/Difficulties (n=68)	Family Members Who Reported Receiving Adequate Help for Symptoms/Difficulties*
Anxiety	61.8	11.9
Feeling apart from/separated from patient	58.8	80.0
Fear	57.4	41.0
Feeling down or depressed	44.1	16.7
Difficulty concentrating	41.2	25.0
Difficulty sleeping	35.3	91.7
Anger	26.5	38.9
Difficulty with household responsibilities	22.1	46.7
Difficulty with child care	11.8	100.0

* Percent calculated using the denominator of how many family members experienced the symptom/difficulty.

Table 27. Symptoms/Difficulties Experienced by Family Members of Individuals Treated on an Outpatient Basis

Symptom/Difficulty	Percentage of Respondents	
	Family Members Who Experienced Symptoms/Difficulties (n=68)	Family Members Who Reported Receiving Adequate Help for Symptoms/Difficulties*
Anxiety	51.6	9.4
Feeling apart from/separated from family members	35.5	77.3
Fear	35.5	54.5
Feeling down or depressed	27.4	58.8
Difficulty concentrating	25.8	-
Difficulty sleeping	25.8	12.5
Anger	14.5	11.1
Difficulty with household responsibilities	11.3	28.6

* Percent calculated using the denominator of how many family members experienced the symptom/difficulty.

The family members rated their own quality of life before and after the patients' radioactive iodine treatment on a 7-point Likert type response scale. The average score for the family member inpatient group prior to the treatment was 6.1 and after the treatment was 5.5. The average score for the family member outpatient group prior to the treatment was 5.7 and after the treatment was 5.7. A statistically significant difference was observed in the inpatient group ($p<0.005$). Comments reflecting the impact on the family member's quality of life include:

> *"Not much impact other than concern for family member [patient].*
>
> *"My husband doesn't have much energy to do things since the treatment."*
>
> *"It was an improvement because now we know what we are dealing with."*
>
> *"...Find it difficult to deal with the mood swings...sometimes she needs a push to tend to her condition. It isn't going to go away on its own."*
>
> *"I believe my husband's disease has led to the break-up of our marriage due to his lack of interest in sex and his extreme irritability."*
>
> *"She is very tired. No sexual desires."*

When asked whether the patient's thyroid disease and treatment had had an influence on them as a family member, 71% of the inpatient group and 75% of the outpatient group indicated there had been no change in lifestyle. For those who experienced a change, the following comments reflect the types of changes in lifestyle:

> *"We try to spend more time together."*
>
> *"Diet has changed and we use nutritional supplements."*
>
> *"Picking up extra work due to my wife's condition, the additional stress of her reactions to medication."*
>
> *"Taking a serious look at what is really important."*
>
> *"Due to uncertainties of his sense of well-being we do not make any plans – just take each day at a time."*

Very few family members in either group indicated there had been a negative impact (see Table 28). The largest proportion of inpatient respondents indicating a negative impact

focussed on the items of leisure (27%), work life (22%), financial status (22%) and mental health (22%). In the outpatient group, the largest proportion of respondents indicated a negative impact on mental health (16%) and household responsibilities (11%). Examples of the type of negative impacts are included in the following comments:

> *"It makes me worry daily that something else will happen."*
>
> *"I was very depressed, as I felt I couldn't help my wife with what she was going through."*
>
> *"We are living at a slower pace now."*
>
> *"Not good, always tired and becomes very cranky, so social life is very limited."*
>
> *"An irritable, debilitated man who takes no interest with his health or diagnosis is a strain to live with. The disease not the iodine treatment is the stress."*

Table 28. Family Members Reporting an Impact on Their Lifestyle Due to Patient's Radioactive Iodine Treatment

Items	Percentage of Respondents Reporting Negative Impact			
	Family Members of Patients Receiving Treatment as an Inpatient (n=68)		Family Members of Patients Receiving Treatment as an Outpatient (n=62)	
	Negative Impact	Not Applicable	Negative Impact*	Not Applicable
Relationship with patient	2.9	2.9	8.1	1.61
Relationship with children	4.4	10.3	6.5	24.2
Relationship with friends	8.8	4.4	6.5	14.5
Employment opportunities	11.8	25.0	4.8	25.8
Work life (paid or volunteer)	22.1	19.1	9.7	22.6
Financial status	22.1	14.7	9.7	17.7
Leisure on retirement time	26.5	13.2	8.1	11.3
Mental health	22.1	8.8	16.1	8.1
Household responsibilities	20.6	8.8	11.3	9.6

* Respondents indicating 1 or 2 on a scale where 1 = negative impact and 5 = positive impact.

5.7 Support

When asked if they had ever felt a need to talk about issues related to the illness and the treatment, 44% of those in the inpatient group indicated they had felt a need. Of those who had felt a need, 67% indicated they had someone with whom they could talk. Twenty-one

percent indicated they talked with another family member while 13% spoke with their family physician. Two (3%) had seen a professional counsellor about issues concerning the patient's thyroid illness. Of the group who had not seen a counsellor, 22% indicated they would like to have seen someone. No one in this group had attended an educational or group session about thyroid disease. Twenty-nine percent indicated they would like to have had that opportunity.

As for the family members in the outpatient group, 57% indicated they had felt the need to talk with someone about the patient's thyroid disease. Of those who had felt the need, 86% indicated they had someone with whom they could talk. Fifteen percent indicated they could talk with other family members and 15% indicated family physicians. Three (5%) family members had been to see a professional counsellor regarding issues about the thyroid illness. Of those who had not seen a counsellor, 15% indicated they would like to have done so. Three (5%) individuals had also participated in an educational or group session about the thyroid disease. Of those who had not attended such a session, 16% indicated that they would like to have done so.

Few family members had accessed the services of the Thyroid Foundation of Canada. Five (7.4%) in the inpatient group and 6 (10%) in the outpatient group has done so. That this may have been helpful is illustrated in the following comment:

> *"Would like to have had some support who you could call and ask questions. We live four hours from the hospital where my parent had surgery and treatment. We just couldn't drop by and ask questions. No self-help group in this area."*

For family members the largest proportion of respondents in both groups indicated that other family members were helpful to them (see Table 29). Other family members included partners, children and other family. Friends were also seen as helpful sources of assistance. Approximately half of the inpatient group (54%) and 44% of the outpatient group cited doctors as helpful to them

Table 29. Sources Family Members Identified Helpful Since Patients' Diagnosis

Sources of Help	Percentage of Family Members' Identifying Sources as Helpful			
	Inpatient (n=68)		Outpatients (n=62)	
	Negative Impact	Not Applicable	Rated 4 or 5*	No response
Partner/Spouse	67.6	8.8	53.2	25.8
Other family	70.6	4.4	50.0	17.7
Children	51.5	16.2	37.1	35.5
Friends	64.7	1.5	41.9	19.4
Nurses	39.7	16.2	19.4	45.2
Doctors	54.4	5.9	43.5	22.6
Self-help groups	7.4	39.7	3.2	75.8
Other patients	13.2	33.8	6.45	72.6
Clergy/Counsellors	19.1	38.2	-	77.4
Canadian Cancer Society	11.8	35.3	3.2	69.4
Literature	19.1	19.1	33.9	33.9
Media (Magazine, TV)	8.82	26.5	14.5	58.1
Thyroid Association	7.4	36.8	8.1	64.5
Nuclear Medicine Technician	32.4	26.5	30.6	43.5

* Respondents indicating 4 or 5 on a scale where 1 = not at all difficult and 5 = extremely difficult

6. Discussion

The purpose of this study was to gather perspectives from patients and family members regarding radioactive iodine treatment. It was seen as important to take such perspectives into consideration during the development of principles for managing the delivery of such therapy. The scope of the survey used for this work included experiences surrounding diagnosis and follow-up as well as the actual delivery of the radioactive iodine itself. Issues of impact on lifestyle and quality of life were also included.

A limitation in this work is the low response rates. The distribution of the surveys was as planned and completed surveys were returned from all provinces where distribution occurred. Although the response rates actually exceed those of general mail surveys where no reminder notices were sent, nonetheless, generalizability of the findings may be somewhat limited.

Another limitation, as is the case with all mailed surveys, is that those who returned the completed forms are likely those individuals with an interest in the topic or individuals who

have the ability to read and articulate responses to a document such as the survey instrument. Thus the findings may underrepresent the views of individuals who are less educated and individuals who lack facility with the English or French languages. In addition, this sample reflects a well-educated Caucasian population.

Every attempt was made in the design of the survey instrument to minimize bias. The response options were written using patients' words derived from the preliminary interviews. Opportunity was provided for additional written responses in many places. Many participants took advantage of this opportunity and provided extensive written comments. Nonetheless, there are several sources of bias which are very difficult to overcome in this type of survey and ought to be kept in mind in interpreting the results. Participants' memory of the actual event may be influenced by subsequent experiences with their illness. Patients and family members may have discussed their responses to the questions prior to returning the survey. And participants may have been influenced by what they were told initially about their treatment and what they understood was required for reasons of safety.

Despite the limitations, this work is the first Canada-wide survey regarding the perspectives of individuals who have received radioactive iodine treatment and of their family members. Responses were received from all provinces where distribution occurred and from a good cross section of community sizes. The results provide interesting insights and have implications for future investigation. Many respondents included written comments reflecting a desire for input into this topic area and the importance of gathering patient and family perspectives.

6.1 Diagnosis

The ratio of female to male respondents approximates the incidence by gender of thyroid disease (Baker and Feldman, 1993) The symptoms respondents cited as being present at the time of diagnosis are typical of the clinical presentation of this disease. The differences in presenting symptoms between the inpatient and the outpatient groups may be understood on the basis of the disease likely to be treated on an inpatient and outpatient basis but must be considered in light of the mix of malignant and non-malignant diagnoses in each group. Individuals with malignant disease are more likely to be treated on an inpatient basis and to receive higher doses of radioactive iodine.

The majority of patients in both groups received a definitive diagnosis within three months of seeking help for their difficulties. That more individuals who eventually were treated as outpatients received their diagnosis within one month likely relates to the fact that diagnostic procedures for non-malignant disease are less complex than those for malignant disease. As well, resources for such procedures as an ultrasound guided biopsy may necessitate waiting for an appointment. Furthermore, there is a "wait and see" approach which may be taken given that benign tumors are extremely common and thyroid tumors grow slowly. Usually there is not a perceived urgency on the part of physicians to get to treatment even with a confirmed cancer.

Although a relatively small proportion of the sample, the patients who were waiting more than three months for a diagnosis faced a prolonged period of uncertainty. It is not clear from the data in this study how distressing this waiting time was for this group of patients or if they understood the reasons for the wait.

6.2 Treatment

The proportion of patients in the inpatient group who underwent partial thyroidectomy is not unusual given that this procedure is commonly performed when a diagnosis is not definitive prior to surgery. If the frozen sections do not allow a definitive diagnosis during the operative procedure, surgeons will often close and perform a second surgery once definitive results are available. Additionally, there is controversy regarding whether a hemithyroidectomy is an adequate operation for papillary cancers, especially if they are small, encapsulated and the patient is young.

A number of patients treated as outpatients underwent surgical procedures indicating treatment for thyroid cancer. That they are in the outpatient group is likely explained by the practice of treating thyroid cancer patients needing ablation of remnants with serial doses of 29.9mCi of I^{131} every 6 to 12 months until ablation is achieved. This practice came from the United States where some patients could not afford the cost of hospitalization. The practice in Canada also may be a response to the availability of beds and the trend of moving procedures to outpatient or ambulatory settings when they were originally provided

in inpatient settings. There is controversy regarding this approach which seems to be a response to bureaucratic regulation and not necessarily the pathophysiology of the disease.

The number of individuals with non-malignant disease who were treated as an inpatient may be explained by the practice of admitting individuals who have co-morbid conditions that would make treating them as an outpatient more difficult. Additionally, if the individual had multinodular disease and requires high doses of radioactive iodine, they are likely to be treated as an inpatient.

Finally, the length of time individuals were off medications prior to receiving radioactive iodine treatment in the inpatient group is consistent with current practice. For patients with malignant disease, the usual interval is 4 to 6 weeks. For those with non-malignant disease the usual interval is 1 to 2 weeks. Many of the problem symptoms respondents cited are linked to this period off medications (i.e., muscles cramps, feeling down, nausea). Clearly this interval being off medications is a difficult one for patients and family members and has implications for patient education and support.

6.3 Precautions During and Following Treatment

At first glance, it is somewhat surprising that precautions were not reported as used by 100% of the respondents. However, the proportion of respondents citing the precautions they used could reflect a number of factors: what the patient observed, what the patient was told to do, what the patient remembered to do, the policies in use at a particular institution and the environmental reality. Additionally, there are variations in the current practices regarding precautions for individuals who received their treatment as an inpatient and an outpatient. This variation possibly relates to the different dosage levels for these two groups of patients and the amount of thyroid tissue the patient possesses. However one would expect similar practices within groups and hence similar sets of instructions about precautions.

Overall, a large proportion of the inpatient group reported similar precautions during the hospital stay. Variation emerged most often around issues like taking showers and having visitors. Currently there are hospitals that still do not have showers in all patient rooms and practices vary from institution to institution about allowing visitors to see patients who are

in isolation. It is concerning that patients are being place in isolation in rooms that do not have shower facilities and that visiting practices are so varied. This latter observation points to the need for evidenced based guidelines regarding visitation for patients who are isolated because of receiving radioactive iodine therapy.

Overall, the patients who were informed and expected to be in isolation did not find it particularly difficult. Of note is that the aspects that made the isolation easier were primarily social in nature: contact with family, friends and professionals; having access to television; having access to a telephone; and windows (with a view) in the room. Clearly there are implications in these suggestions for institutions providing inpatient radioactive iodine treatment. Key strategies include making certain patients have the correct information about isolation and receive it in a timely and sensitive manner. Timely communication during isolation is also critical.

Overall, the aspects surrounding the precautions that patients found difficult concerned not being able to do what they normally do, being off their usual thyroid medications, and not being able to get close to family members. These types of difficulties reflect interference with normal daily activities and are the type of difficulty frequently cited by patients who are undergoing other types of treatment. Disruption in usual life activities often evokes frustration and distress and the potential for distress increases the longer the treatment interval lasts. Health care providers need to be aware of these issues and help patients plan for them prior to treatment. In addition, interpretation of the precaution of not getting "close" to family and friends may be linked to how "keeping your distance" was explained to the patients. Health care providers may need to provide concrete examples of what this means (e.g., an arm's length).

The concerns respondents identified about being at home following radioactive iodine therapy and the possibility of receiving treatment on an outpatient basis were remarkably similar. Family members also cited the same type of concerns. Most of the issues related to worry that others would receive a dose of radiation, wondering how to know when the radiation was gone, and wondering what the radiation would do to the rest of the patient's body. Clearly these issues have implications for patient education or perhaps the use of personal monitors.

6.4 Impact of the Illness and Treatment

Overall, the inpatient group cited more problem areas than did the outpatient group. Many of the physical symptoms the inpatient group cited could be related to being off their thyroid medication and therefore hormone deprived. This includes feeling down, difficulty concentrating, muscle cramps, and nausea. In addition, the inpatient group received higher doses of I^{131} and many were facing a cancer diagnosis. However, what is most concerning about these data, is the proportions of patients in both groups who did not receive adequate help for the difficulties they experienced. Patients in both groups had concerns and were dealing with issues, yet adequate assistance was not forthcoming in all cases. It is not clear in the survey data whether the problems were not identified by health care professionals, whether the health care professionals were aware of the problems and did not know interventions that could help, or whether the interventions that were implemented were not useful. In any case, there is much room for improvement. Strategies may need to be focused on increasing the awareness of health care providers about the difficulties patient face, implementing strategies for assessment of patient concerns, ensuring appropriate interventions and referrals are offered and identifying new and effective interventions through research efforts.

The larger proportion of inpatients who indicated an impact on lifestyle is likely related to the diagnosis of cancer itself. Many respondents wrote about the shock of the diagnosis and the impetus they felt to think about life priorities. This is not unusual for individuals confronted by a cancer diagnosis. The issues of facing a potentially life-threatening disease frequently provide a stimulus to reorder one's priorities and make lifestyle changes. Often those changes are aimed at living a healthier life style than in the past. Changes are made in areas such as diet, number of hours worked, and exercise routines.

Overall, relatively few individuals indicated a negative impact on their lives. The largest proportion of individuals who experienced an negative impact indicated it was experienced in the areas of work life, financial status, leisure time and mental health. This is similar to findings in other patient populations (Gray, et al, 1997b; Fitch, et al, 1999). The diagnosis of disease and the reflections about its implications often bring about closer relationships with family and friends, accounting for the sense of positive impact. However, loss of time

at work influences financial status and the worries associated with illness and its outcomes have an impact on mental health. The challenge for health care providers is to help patients plan for the episode of treatment and to identify those individuals who are experiencing a particularly difficult time.

Overall, the quality of life scores were not significantly different for either inpatient or outpatient respondents following diagnosis and treatment. This may relate to the ability of individuals to return to a relatively usual existence following their treatment time as well as the ability for many to make changes in their lifestyle which they perceive as positive changes. That the family members' quality of life scores were significantly different for the inpatient group is more difficult to explain.

6.5 Communication and Access to Information

Many respondents in both the inpatient and the outpatient group indicated they felt informed about their disease, treatment and side effects and felt they had someone with whom they could talk about these matters. Overall they expressed satisfaction with the communication style of the health care professionals with whom they can in contact. However, there were groups of respondents who did not have the explanations they felt they needed, did not have individuals with whom to talk and were not satisfied with the communication of the health care providers. The challenge for health care providers is to be able to identify this group who need more information and find approaches to meet their needs.

Information and communication become critical issues if more patients are to be treated on an outpatient basis. At home patients may not have access to the range of health care professionals they may have if they are hospitalized for treatment. Family physicians will need to be highly involved in the care at home and be able to respond to patient questions and concerns. There may be need to establish special telephone contact procedures and information links for patients receiving care at home as well as nurse visits arranged during the treatment period.

Clearly information was perceived as important for both individuals treated as an inpatient or as an outpatient. They were relatively satisfied about the information they received

concerning their medical condition, tests, procedures, treatment choices and side effects of treatment. However, they were less satisfied with the information they received concerning emotional reactions, support available for them and steps they could take to cope with their situation. These observations have implications for the patient education and the type of health care professional with which the patient comes in contact. Nurses, nutritionists and social workers may need to be part of the treatment teams for this patient population. In addition, information for family physicians may be indicated to ensure patient and family member fears can be reduced as early as possible. The initial discussions about disease and treatment options can have significant impact on patient and family responses.

More than half of the respondents indicated a need to talk to someone else about issues related to their disease. Many had someone with whom they could talk and a few were able to see a professional counsellor. Very few individuals had the opportunity to attend a self-help group or to access the services of, for example, the Thyroid Foundation of Canada or the Canadian Cancer Society. Both of these organization provide services to patients, especially in terms of patient information. A challenge for those providing care to this population of patients is to ensure the patients and families are aware of community services which are available to them and how those services can be accessed. The challenges for the agencies is to provide sensitive, culturally appropriate services.

6.6 Family Issues

The family members who responded to the survey provided answers regarding their own needs and concerns about radioactive iodine treatment. The data provide evidence that the disease and treatment have an impact on family members as well as the patient.

The family members did not express the same level of satisfaction about communication and access to information. This likely relates to their access to, and interaction with, health care professionals. They may well have been dependent upon the patient to share and interpret information for them. Overall they perceived information as important yet were less than satisfied with what they received across all topic areas. Clearly there are implications in these observations for health care providers about communicating with family members and about providing written information regarding a range of topics related

to radioactive iodine therapy. Many of the topics family members wanted to know more about were the same as those identified by patients.

Of interest, many of the concerns family members expressed about the radioactive iodine treatment were the same as those expressed by the patient. Primarily, they worried about whether the radiation was gone from the home and whether the treatment worked. Family members also experienced difficulties around the patient being off medication, the patient being in hospital and the issue of not being able to get "close" to the patient. In all likelihood, interventions developed to help patients with these concerns will also be of use to family members.

Family members reported their own difficulties during the radioactive iodine treatment. Many of the reported difficulties were indications of psychosocial distress (i.e., anxiety, fear, feeling down, etc). It is concerning that so few family members received adequate help for these issues. It is unclear from the survey data whether family members were in contact with health care professionals regularly, whether the issues were identified by health care professionals, whether interventions were implemented or whether interventions were not effective. Further work is needed to pinpoint the gaps in the care process for family members.

The patterns of negative impact reported by family members were similar to those reported by the patients themselves although the actual proportions were smaller. Overall the negative impact was experienced by a relatively small proportion of individuals. The domains where negative impact was experienced were work, finances, leisure, mental health. Practice challenges exist in identifying the individuals who experience the negative impact as soon as possible.

Fairly large proportions of the family members expressed the need to talk with someone about issues related to the disease and treatment. Although a sizeable number of those individuals had someone with whom they could talk, a proportion did not have anyone. Very few family members had the opportunity to see a professional counsellor, attend a support or educational group or access the Thyroid Foundation of Canada or the Canadian Cancer Society. These observations have implications for family education and providing information about community services.

6.7 Conclusion

The Canada-wide study provided perspectives from patients and family members about their experiences regarding radioactive iodine therapy. The data indicate variation in patient and family member perceptions about how precautions are to be implemented. Both patients and family members expressed the desire for more information regarding many aspects of the treatment experience given the current modes of delivering treatment. With movement toward more outpatient treatment delivery there are critical implications for education of health care professionals, patients and family members. Additionally, there are implications in terms of support for both patients and family members in terms of dealing with the psychosocial issues which emerge in living with thyroid disease.

References

Baker, K.H. & Feldman, J.E. (1993). Thyroid cancer: A review. Oncology Nursing Forum. 20(1):95-104.

Barrington, S.F., Kettle, A.G., O'Doherty, M.J., Wells, C.P., Somer, E.J.R., & Coakley, A.J. (1996). Radiation dose rates form patients receiving iodine-131 therapy for carcinoma of the thyroid. European Journal of Nuclear Medicine 23(2).

Barrington, S.F., Kettle, A.G., Thomson, W.H., Burrell, D.N., Batchelor, S., Mountford, P.J., O'Doherty, M.J. & Harding L.K. (1996(b)). RPC guidelines on radiation protection following radioiodine therapy for thyrotoxicoisis: Are they appropriate? (abstract) Nuclear Medicine Communications 17 276.

Carey, J.L., Kumpuris, TM., Wrobel, M.C. (1995). Release of patients containing therapeutic dosages of iodine – 131 from hospitals. Journal of Nuclear Medicine Technology. 23(23) 144-149.

Culver, C.M., Dworkin, H.J. (1992). Radiation safety considerations for post iodine-131 thyroid cancer therapy. Journal of Nuclear Medicine, 33(7). 1402-1405

Dow, K.H., Ferrel, B.R., & Anello, C. (1997a). Quality of life changes in patients with thyroid cancer after withdrawal of thyroid hormone therapy. Thyroid, 7(4), 613-619.

Dow, K.H., Ferrel, B.R., & Anello, C. (1997b). Balancing demands of cancer surveillance among survivors of thyroid cancer. Cancer Practice, 5(5), 289-295.

Fitch, M.I., Gray, R.E., DePetrillo, A.D., Franssen, E. & Howell, D. (1999). Canadian women's perspectives on ovarian cancer. Cancer Prevention & Control, 3(1):52-60.

Gaskill, D., Henderson, A., & Fraser, M. (1997). Exploring the everyday world of the patient in isolation. Oncology Nursing Forum, 24(40), 695-700.

Gray, R.E., Fitch, M., Davis, C. & Phillips, C. (1997a). A qualitative study of breast cancer self-help groups. Psycho Oncology, 6, 279-289.

Gray, R.E., Klotz, L.H., Iscoe, N.A., Fitch, M.I., Franssen, E., Johnson, B.J., Labrecque, M. (1997b). Results of a survey of Canadian men with prostate cancer. The Canadian Journal of Urology, 4(2), 250-258.

Gray, R.E., Greenberg, M., Fitch, M.I., Sawka, C.A., Hampson, A., Labrecque, M., Moore, B. (1998). Information needs of women living with metastatic breast cancer. Cancer Prevention and Control, 2(2), 57-62.

Group of Medical Advisers to the Atomic Energy Control Board. (1993). GMA-4 Guidelines on the management of patients treated with iodine-131. INFO-0442.

Jenner, E. (1990). Aspects of isolation care. Nursing 4(20). 17-22.

Knowles, H. (1993). The experience of infections patients in isolation. Nursing Times, 89(30), 53-56.

Register, C. (1987). Living with chronic illness. New York: Bantam Books.

Reiker, P., Clark, E., & Fogelberg, P. (1992). Perceptions of quality of life and quality of care for patients with cancer receiving biological therapy. Oncology Nursing Forum, 19, 433-440.

Streiner, D.L. & Norman, G.R. (1989). Health measurement scales: a practical guide to their development and use. New York: Oxford.

Wood, L.C. (1998). Support groups for patients with graves' disease and other thyroid conditions. Endocrinology and Metabolism Clinics of North America, 27(1), 101-107.